Adding life to years

VALORIZATION ADDENDUM

In this chapter, important findings of this dissertation and their societal value are addressed. Furthermore, future directions for quality of life- and quality of care assessment are elaborated on. This chapter concludes with a description of activities for the dissemination of this dissertation's findings.

Quality of life and long-term care in the Netherlands

This dissertation provides an enhanced understanding of the quality of life of people with dementia receiving long-term care. Quality of life and quality of care are irrevocably linked to each other, as a good quality of life is the ultimate goal of good care. Quality of life and quality of care in Dutch nursing homes received major attention recently. In 2014, Martin van Rijn, the Dutch State Secretary for Health, Welfare, and Sport launched the program 'Dignity and Pride' ['Waardigheid en Trots']. This program was written in response to concerns about the quality of nursing home care and aimed to improve the lives of and care provided to Dutch nursing home residents. This dissertation actively responds to the often negative view society holds about the quality of life of people with dementia in long-term care. Although dementia and living in a care facility are characterized by loss and the capacity of people with dementia and their relatives to adapt to their situation is challenged, there remain possibilities to have a good life. This dissertation found that many people with dementia spend a large part of their day engaging in activities or social interactions. When compared with other European countries, Dutch people with dementia and their caregivers value the quality of life of the person with dementia comparably – and sometimes even better.

In addition to quality of life of nursing home residents, this dissertation focused on people with dementia who are living at home but at risk for imminent admission. It was found that these people's quality of life is comparable to the quality of life of those living in a long-term care facility. However, as the Dutch government increasingly encourages people to 'age in place' or, in other words, to live at home for as long as possible, people with dementia who live at home will become increasingly dependent. Consequently, it will become more challenging for them to live a good life at home. Therefore, the quality of life of people with dementia who live at home should receive major attention and supporting social networks plays a key role in this. Informal caregivers are the ones who people with dementia primarily rely on, especially in the later stages of their dementia. These informal caregivers should not only have easy access to support from care professionals, but should also receive support from their own social networks and fellow informal caregivers.

Quality of life and quality of care: future directions

Policy makers, caregivers, and researchers should remain focusing on quality of life and quality of care as there remains room for improvement. As a first step for improved quality of life and quality of care, this dissertation advocates for these concepts to be defined and assessed differently.

First, detailed insight into well-being in 'the here and now' is more valuable than quality of life assessments which use broad questionnaires alone. This is especially the case when evaluating well-being interventions that aim to improve situations in the here and now rather than on the long term. This is especially important because people with dementia often have a limited capacity to recall past events. In this dissertation, mood was used as an indicator for well-being, however further research is necessary to investigate whether this is enough or whether other aspects should also be taken into account. For example, it has repeatedly been suggested that engagement should be part of the well-being construct.

Second, when evaluating quality of care, interpersonal aspects of caregiving such as communication and respect should be taken into account. The social interactions that were assessed in this dissertation could be regarded as indicators for quality of care. However, it has not yet been investigated which interpersonal aspects of caregiving constitute 'good' quality of care and more research into this is necessary. The Maastricht Electronic Daily Life Observation-tool (MEDLO-tool) used in this dissertation contains a scale for assessing the quality of social interactions. However, this scale does not appear sensitive enough as there is little variation in the scores regarding the quality of social interactions. Consequently, it is very difficult to assess whether there is room for improvement in the communication between caregivers and people with dementia. It is important to investigate how these interpersonal aspects of caregiving could be assessed more sensitively.

Once well-being and quality of (interpersonal) care are more clearly defined, the MEDLO-tool could function as a vehicle for nursing staff to assess which aspects of interpersonal caregiving have a positive influence on the well-being of people with dementia. This information will provide valuable information for quality of care improvements. Nursing staff could use the MEDLO-tool to observe people with dementia and their interactions with other nursing staff. However, several steps should be taken before the MEDLO-tool can be used in this way. Primarily, it should be adapted to make it easier for nursing staff to use. In particular, the analyses of associations between levels of well-being and interpersonal caregiving may be challenging for nursing staff without an academic background. A tablet application which automatically provides insight into these relationships could be developed for this purpose. After the tool becomes easier to use, nursing staff members who perform observations should be able to communicate the aspects of interpersonal caregiving which contribute to or harm the well-being

of nursing home residents with dementia. To do so, they should be trained to appropriately communicate their findings to the nursing staff they observed.

Dissemination

To disseminate the results of this dissertation to nursing staff, policy makers, researchers, and other interested people, several steps will be taken. First, an accessible summary of the results will be distributed among all long-term care organizations who are member of the 'Living Lab in Aging & Long-Term Care' in the province of Limburg. The summary will be in the newsletter of this organization, and will also be available on their website (https://www.academischewerkplaatsouderenzorg.nl). Second, a summary of this dissertation will be available on other websites, such as the website of the Internationale Stichting Alzheimer Onderzoek (https://www.alzheimer.nl/) and the website of Alzheimer Nederland (http://www.alzheimer-nederland.nl). Third, the two large datasets that underlie this dissertation will be available to colleagues and students. The existing datasets contain much information in underexplored areas. For example, there is unused data available about the quality of life of people with dementia who made the transition from home to nursing home and the use of physical restraints on people with dementia who live at home. In addition, the detailed descriptions of communication between people with dementia and formal caregivers could be used for further research.